

# OF INFORMATION, TRUST, AND ICE CREAM: A RECIPE FOR A DIFFERENT PERSPECTIVE ON THE PRIVACY OF HEALTH INFORMATION

Jana Sutton\*

*The concept of privacy is inescapable in modern society. As technology develops rapidly and online connections become an integral part of our daily routines, the lines between what may or may not be acceptable continue to blur. Individual autonomy is important. We cannot, however, allow it to suffocate the advancement of technology in such vital areas as public health. Although this Note cannot lay out detailed instructions to balance the desire for autonomy and the benefits of free information, it attempts to provide some perspective on whether we are anywhere close to striking the right balance. When the benefits of health information technology are so glaring, and yet its progress has been so stifled, perhaps we have placed far too much value—at least in the health care context—on individual privacy.*

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\* J.D. Candidate, University of Arizona James E. Rogers College of Law, 2014. Thank you to the brilliant professors here for their relentless efforts to inspire, guide, and encourage; to my classmates for their unending supply of help and humor; and to my infinitely patient husband for far more than I could possibly fit into a footnote.

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### INTRODUCTION

Bob wants ice cream, so he looks online to find out how late the store is open. He also looks up the number for a cab. The information for both is readily available at a quick glance. When he arrives at the store, Bob meticulously inspects each package of ice cream and notes the clear lists of ingredients, calories, and vitamins, or lack thereof. Or maybe he skips the reading and goes straight for the most delicious-looking picture. Either way, Bob is happy with his purchase.

As he walks out the door, however, Bob is hit by a truck. Despite this unfortunate turn of events, Bob is at least comforted during the ambulance ride by the thought that the hospital will have access to his health information and will therefore be able to give him the best possible treatment. They will also, surely, keep everything confidential. Or will they?

Information has value. In all fields—from health care, science, philosophy, and business, to education, where teachers strive to satisfy the insatiable curiosity of each small child—information provides answers that improve our lives. As technology improves, the flow of that valuable resource continues to expand rapidly. But, despite humanity’s thirst for knowledge, the unrestricted flow of information presents questions of trust. Who has access to certain types of information? And—perhaps a more disconcerting question—who has personal information about *you*?

Bob did not mind having the chance to peek at the grocery store’s business hours from the comfort of his couch. He did not mind having access to the ingredient list for every flavor and brand of ice cream. Bob likes to have information. But Bob, being the paranoid type, might mind if the store tracked his web search or if it made note of which flavor of ice cream he purchased for advertising purposes. Bob might be disturbed to know that the cab company kept a record of where he lives and that the hospital has access to, and control over, Bob’s entire medical history.

At a glance, this transaction seems fair—Bob receives information and help in exchange for his own personal information—but this does not solve the trust issue. Bob is still worried. To solve that issue, Bob is missing an important ingredient: What Bob does not have is information about *his* information. He has no way to know what information he is sharing or what his information is being

used for. He worries about what, if anything, might happen if his medical records are released. How can Bob's trust in information technology be restored?

This Note will discuss how knowledge, awareness, and transparency affect trust and support for the free flow of information. Specifically, this Note will discuss health information and how the regulation of health information technology ("HIT") affects health efficiency, effectiveness, and patients' health choices. Part I will discuss the current state of health information privacy regulations and briefly address the history of those regulations. Part II will then address why the regulation of HIT should promote transparency, efficiency, and trust. Finally, Part III will show how major changes in the regulation of HIT could accomplish these goals.

A legislative focus on disclosures and transparency, rather than control and consent, for health care privacy reform can improve information flow and promote trust between patients, their doctors, and the health care system as a whole. Opening the flow of health care information towards both health care providers *and* patients could improve patient outcomes while reducing health care costs.

## I. THE CURRENT STATE OF HEALTH INFORMATION PRIVACY

Health information and the technology that stores, organizes, and transfers it are subject to various restrictions and regulations. At one time, health care privacy was almost entirely regulated by the common law<sup>1</sup> and by a smattering of various state laws and regulations.<sup>2</sup> The common law, however, proved slow, inconsistent, and inadequate when applied to fast-paced advances in technology.<sup>3</sup> The Health Information Privacy and Accountability Act of 1996

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1. Ilene N. Moore et al., *Confidentiality and Privacy in Health Care from the Patient's Perspective: Does HIPAA Help?*, 17 HEALTH MATRIX 215, 219–27 (2007); see, e.g., *Doe v. Cmty. Health Plan–Kaiser Corp.*, 268 A.D.2d 183, 186–87 (N.Y. App. Div. 2000); see also Andrew J. McClurg, *A Thousand Words Are Worth a Picture: A Privacy Tort Response to Consumer Data Profiling*, 98 NW. U. L. REV. 63, 98 (2003) (discussing the benefits and problems with tort law as a remedy for violations of privacy related to information tracking).

2. See Amalia R. Miller & Catherine Tucker, *Privacy Protection and Technology Diffusion: The Case of Electronic Medical Records*, 55 MGMT. SCI. 1077, 1083 (2009); Joy L. Pritts, *Altered States: State Health Privacy Laws and the Impact of the Federal Health Privacy Rule*, 2 YALE J. HEALTH POL'Y L. & ETHICS 325, 327 (2002) ("Until the recent promulgation of [the Health Information and Portability and Accountability Act], states have been the primary regulators of health information through their constitutions, common law, and statutory provisions.").

3. See Moore et al., *supra* note 1, at 227. Despite their shortcomings, the common law and state statutes still provide restrictions and remedies for breaches of physician–patient confidentiality and other privacy-related concerns. See, e.g., *Doe v. Marselle*, 675 A.2d 835, 836, 840–43 (Conn. 1996) (analyzing a physician's breach of confidentiality under Connecticut General Statutes § 19a-583). Like the Health Information and Portability and Accountability Act, however, these solutions also often focus on restrictions and harms rather than improving the flow of information. See Pritts, *supra* note 2, at 332–40. Because HIPAA, as the federal standard, supplies states with the least

(“HIPAA”) helped solve these problems by creating a uniform, national health information privacy law.<sup>4</sup> HIPAA, however, also introduced a few new problems of its own.

When it was first conceived, HIPAA had many purposes. Primarily, it was created as a national attempt to solve a national problem: health care costs. Congress designed HIPAA to encourage the use of Electronic Health Records (“EHRs”) under the theory that EHRs would allow health care providers to become more efficient and effective.<sup>5</sup> HIPAA was not, however, limited to improving health care efficiency. With information flowing more openly, Congress recognized the risk that it would shake consumer confidence if it failed to address the privacy concerns related to the efficient flow of individuals’ health information.<sup>6</sup> Thus, the HIPAA Privacy Rule was born.<sup>7</sup>

The original Privacy Rule focused almost entirely on the disclosure of certain types of health information by certain types of health care providers, and individuals’ control and consent over the use of their information.<sup>8</sup> HIPAA’s Privacy Rule was then expanded by the Health Information Technology for Economic and Clinical Health Act (“HITECH”) of 2009.<sup>9</sup> Congress designed HITECH to provide stronger consequences for any breach of HIPAA’s Privacy Rule.<sup>10</sup>

HITECH also, however, marked Congress’s first attempt to provide a better connection between patients and their own health information. HITECH allowed the Department of Health and Human Services (“HHS”) to create new

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information-restrictive approach states can use to regulate health information, this Note will begin with HIPAA. Individual state laws that may go above and beyond HIPAA’s restrictions should also be carefully scrutinized to weigh whether the burdens they impose on the flow of information provide any significant benefits.

4. Health Insurance Portability and Accountability Act of 1996, Pub. L. No. 104–191, 110 Stat. 1936 (1996) (codified as amended in scattered sections of 18 U.S.C., 26 U.S.C., 29 U.S.C., and 42 U.S.C.).

5. Bob Brown, *New Technologies Have Created New Threats to Electronic Protected Health Information*, 11 J. HEALTH CARE COMPLIANCE 35, 35 (2009) (“[T]he new provisions are intended to provide the necessary privacy and security framework that will allow for the continued application of information technologies to help achieve the main goal of the administrative simplification provisions of HIPAA: to improve the efficiency and effectiveness of the health care system.”).

6. Moore et al., *supra* note 1, at 247.

7. General Administrative Requirements, 45 C.F.R. pt. 160 (2013); Security and Privacy, 45 C.F.R. pt. 164; see U.S. DEP’T OF HEALTH & HUMAN SERVS. OFFICE FOR CIVIL RIGHTS, SUMMARY OF THE HIPAA PRIVACY RULE 1 (2003).

8. See U.S. DEP’T OF HEALTH & HUMAN SERVS. OFFICE FOR CIVIL RIGHTS, *supra* note 7, at 1.

9. 45 C.F.R. §§ 160–69 (2013).

10. Anna L. Spencer, *Responding to Challenging Aspects of HITECH’s Modifications to HIPAA*, in RECENT DEVELOPMENTS WITH HIPAA: LEADING LAWYERS ON INTERPRETING THE NEW HIPAA LAWS, DEVELOPING EFFECTIVE COMPLIANCE STRATEGIES, AND RESPONDING TO RECENT ENFORCEMENT ACTIONS 129, 132 (2010); Brown, *supra* note 5, at 35–36.

regulations that would financially reward health care providers that adopted EHRs, while subjecting those who do not adopt EHRs to financial penalties.<sup>11</sup> HHS took on that responsibility by requiring health care providers to show that they were meeting certain “meaningful use” requirements for EHRs.<sup>12</sup> These meaningful use requirements, released in three stages, have popular, widely accepted, and extremely beneficial ends in mind. The means HHS requires health care providers to use to achieve those ends, however, have been met with confusion and criticism.<sup>13</sup>

Even with this newfound focus on patient access to health information, the direction that Congress has taken with information privacy, particularly in the health care context, seems clear: restrict, protect, and enforce. Despite its focus on granting patients access to their health records, HHS has, so far, shown very little consideration for ideas that might improve patients’ understanding of how their information is stored, used, or shared.

#### *A. Legislative Intent: What We Wanted to Accomplish*

When it adopted HIPAA, and later HITECH, Congress had two major goals. First, Congress wanted to reduce health care costs and improve patient outcomes by promoting the meaningful use of EHRs. Second, and secondarily, Congress thought to add a Privacy Rule that would help protect patients’ EHRs from unwanted disclosure.

##### *1. Efficiency and Cost Savings*

One of the primary goals of HIPAA was to promote efficiency. Congress intended to both reduce costs and improve patient outcomes by adopting EHRs.<sup>14</sup>

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11. CTRS. FOR MEDICARE & MEDICAID SERVS., MEDICARE ELECTRONIC HEALTH RECORD INCENTIVE PAYMENTS FOR ELIGIBLE PROFESSIONALS (2013); CTRS. FOR MEDICARE & MEDICAID SERVS., PAYMENT ADJUSTMENTS & HARDSHIP EXCEPTIONS TIPSHEET FOR ELIGIBLE PROFESSIONALS 1–5 (2013).

12. Nicolas P. Terry, *Anticipating Stage Two: Assessing the Development of Meaningful Use and EMR Deployment*, 21 ANN. HEALTH L. 103, 104–05 (2012); *Policymaking, Regulation, & Strategy: What is Meaningful Use*, HEALTHIT.GOV, <http://www.healthit.gov/policy-researchers-implementers/meaningful-use> (last visited Sept. 30, 2013).

13. See Terry, *supra* note 12, at 117–18. Despite widespread agreement with the ideals represented by the meaningful use standards, many health care providers question whether the standards are realistic, especially considering the time limits for accomplishing such lofty goals. See Charles Fiegl, *Proposed Meaningful Use Stage 3 Criticized as Hasty and Too Strict*, AMEDNEWS.COM (Jan. 28, 2013), <http://www.ama-assn.org/amednews/2013/01/28/gvl10128.htm> (“[W]hat the [committee] proposes seems more like science fiction than mere forward thinking. . . . Indeed, the proposals seem ambitious and imaginative, but almost impossible to actually accomplish, especially without much in the way of underlying data, interoperability and communication standards.”) (brackets in original, quotation marks and citation omitted).

14. HIPAA was created to:

[I]mprove the portability and continuity of health insurance coverage in the group and individual markets, to combat waste, fraud, and abuse in

Depending on which factors researchers take into account, studies vary on the exact cost savings that could result from promoting the use of EHRs. Estimated cost savings range anywhere from \$34 billion<sup>15</sup> to \$371 billion per year, and those savings could come from several areas.<sup>16</sup> For example, proponents argue that EHRs allow health care providers to conduct fewer unnecessary or repeated medical tests.<sup>17</sup> EHRs may also allow health care providers to have faster access to a patient's family history and drug allergies, which saves health care providers' time when making diagnoses and developing treatment plans.<sup>18</sup> On a more simple level, EHRs help reduce errors and wasted time caused by illegible, hand-written notes; the slow speed of fax machines; and the need to re-explain symptoms between various health care providers working with the same patient.<sup>19</sup>

Even aside from cost savings, proponents for broadly adopting EHRs point out that EHRs provide other potential benefits, such as health and safety.<sup>20</sup> One study, for example, found that a mere 10% increase in the adoption of EHRs in the neonatal context would prevent "16 deaths per 100,000 live births" at a cost of \$531,000 per baby saved.<sup>21</sup> EHRs also help prevent adverse drug effects, increase patient participation in preventative care and other health care

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health insurance and health care delivery, to promote the use of medical savings accounts, to improve access to long-term care services and coverage, to simplify the administration of health insurance, and for other purposes.

HIPAA, Pub. L. No. 104-191, 110 Stat. 1936 (1996); Moore, *supra* note 1, at 227.

15. Miller & Tucker, *supra* note 2, at 1077, 1080 (taking into account the cost savings produced by having faster access to health information and avoiding duplicate tests).

16. See Richard Hillested et al., *Can Electronic Medical Record Systems Transform Health Care? Potential Health Benefits, Savings, and Costs*, 24 HEALTH AFF. 1103, 1106, 1112 (2005) (comparing potential productivity increases in health care to those experienced in other industries, such as retail and telecommunications, as they adopted IT, as well as accounting for the increased productivity of patients who would be out of the hospital and back to work or school faster after receiving more efficient and effective health care).

17. Miller & Tucker, *supra* note 2, at 1077.

18. Hillested et al., *supra* note 16, at 1110.

19. Sameer Kumar & Krista Aldrich, *Overcoming Barriers to Electronic Medical Record (EMR) Implementation in the US Healthcare System: A Comparative Study*, 16 HEALTH INFORMATICS J. 306, 314 (2010).

20. Hillested et al., *supra* note 16, at 1108-14.

21. AMALIA R. MILLER & CATHERINE E. TUCKER, SOCIAL SCIENCE RESEARCH CENTER, *CAN HEALTHCARE IT SAVE BABIES?* 3 (Apr. 14, 2011); but see generally Michael F. Furukawa, *Electronic Medical Records and the Efficiency of Hospital Emergency Departments*, 68 MED. CARE RES. AND REV. 75 (2010) (finding less compelling evidence that patient outcomes improve when health information technology is used in hospital emergency departments); Karl Pillemer et al., *Effects of Electronic Health Information Technology Implementation on Nursing Home Resident Outcomes*, 24 J. AGING & HEALTH 92 (2011) (speculating that, despite inconclusive results, health information technology might have adverse effects on seniors in nursing homes).

appointments, and help patients monitor their own health.<sup>22</sup> Some observers even argue that the principal benefit of EHRs could be their non-cost-related benefits. EHRs may, for example, allow for a more patient-centered care dynamic, open doctor–patient communication channels, encourage patients to take more responsibility for their own care, and make disease or chronic condition management more common and accessible.<sup>23</sup>

## 2. Protecting Privacy

In what might be considered an “afterthought,” Congress also implemented the HIPAA Privacy Rule.<sup>24</sup> The Privacy Rule was Congress’s attempt to balance its desire to improve the flow of information through EHRs with its desire to maintain consumer confidence by curbing the potential misuse of health information.<sup>25</sup> The Privacy Rule, however, combined with the subsequent regulations intended to improve it, focuses almost entirely on ensuring consumer confidence by restricting access to information instead of granting access to information.<sup>26</sup> By focusing on restrictions, the Privacy Rule ignores the opportunity to encourage consumer trust through transparency.

The expectation that consumers desire confidentiality with respect to their personal health care information begins with the traditional doctor–patient relationship.

[The] ethos of confidentiality derives from privacy interests of the patient. Privacy, generally described as “the right to be let alone,” is linked to autonomy, i.e., the ability to control one’s destiny and limit others’ physical access to one’s person or to information about oneself. Privacy is a complex and multifaceted concept which

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22. See Hillested et al., *supra* note 16, at 1108–14.

23. See Jaan Sidorov, *It Ain’t Necessarily So: The Electronic Health Record and the Unlikely Prospect of Reducing Health Care Costs*, 25 HEALTH AFF. 1079, 1083 (2006) (“The EHR’s greatest promise arguably lies in the support of these initiatives, versus the prospect of less efficiency, greater cost, inconsistent quality, and unchanged malpractice burdens resulting from a simple engraftment onto the current health care system.”); see also Jenny Gold, *For Patients, What a Difference a Note Makes*, KAISER HEALTH NEWS (Oct. 2, 2012), <http://capsules.kaiserhealthnews.org/index.php/2012/10/for-patients-what-a-difference-a-note-makes>. See generally Tom Delbanco et al., *Inviting Patients to Read Their Doctors’ Notes: A Quasi-experimental Study and a Look Ahead*, 157 ANNALS OF INTERNAL MED. 461 (2012).

24. Moore et al., *supra* note 1, at 247.

25. See *id.*

26. HIPAA does have some, limited, disclosure requirements that give patients access to certain information. HIPAA, for example, requires that health care providers grant patients access to their own health records. Access of Individuals to Protected Health Information, 45 C.F.R. § 164.524 (2013). It also requires that certain health care providers disclose certain information about unintentional breaches. Notification to the Secretary, 45 C.F.R. § 164.408 (2013). These provisions, however, are extremely limited and not well known. They therefore do not have much, if any, impact on consumer trust. See *infra* Part III.B.

scholars have struggled to tease apart and break down into its elements.<sup>27</sup>

The goal for HIPAA was therefore to assure individual health care consumers that their autonomy would remain intact despite the newly rampant dissemination of health care information. HIPAA executed that goal based on the theory that consumers would be satisfied with these confidentiality-oriented protections.<sup>28</sup>

The goals Congress had in mind when it created federal health information regulation—cost reduction, improved safety, better health outcomes, and improved consumer confidence in the system through strong privacy protections—are derived from good intentions and commendable efforts. Whether HIPAA accomplished any of those goals, and to what extent it satisfies them, however, is still a question subject to debate.

### ***B. Practical Effects: What We Have Accomplished***

In its attempt to strike a balance between information accessibility and privacy, Congress missed the mark. By focusing only on the restriction of information, the Privacy Rule swallowed the original intentions of HIPAA and became a catch-all concept that enabled health care providers to deny patients, their family members, their friends, and anyone else access to any information at all.<sup>29</sup> Although the changes in HIPAA brought on by HITECH attempted to solve some of these problems, it is unclear whether those regulations have produced, or ever will produce, any progress in Congress's goals to improve public access to health information, provide greater protection for patients' privacy, decrease health care costs, or improve patient outcomes.<sup>30</sup>

#### *1. Reducing Costs*

First, there is little evidence that HIPAA has adequately encouraged the use of EHRs.<sup>31</sup> Although Congress sought to encourage every health care provider

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27. Moore et al., *supra* note 1, at 221.

28. See Deven McGraw et al., *Privacy as an Enabler, Not an Impediment: Building Trust into Health Information Exchange*, 28 HEALTH AFF. 416, 417–18 (2009) (theorizing that even stronger protections and restrictions on the release of health care information would promote consumer confidence and trust).

29. Jane Gross, *Keeping Patients' Details Private, Even From Kin*, N.Y. TIMES, Jul. 3, 2007, at A12 (“A hospital spokeswoman, Elena Mesa, was asked if nurses were following Hipaa [sic] protocol when they denied adult children information about their parents. She could not answer the question, Ms. Mesa said, because Hipaa [sic] prevented her from such discussions with the press.”).

30. See Lynn S. Muller, *The Ever-Changing Legal Landscape*, 17 PROF. CASE MGMT. 33, 33 (2012); Brown, *supra* note 5, at 35.

31. See Kumar & Aldrich, *supra* note 19, at 314–15 (suggesting alternative congressional action, such as offering interest-free loans to purchase EHR technology or mandating the adoption of EHRs, that would adequately encourage health care providers to adopt EHR technology).



to use EHRs by 2014, the likelihood of achieving that goal, despite vast, congressionally approved economic incentives, is poor.<sup>32</sup> Consequently, if few health care providers use EHRs, then the cost savings and improved patient outcomes associated with the use of EHRs cannot be realized.<sup>33</sup>

To the contrary, there is even evidence that the health care industry has been negatively impacted in terms of cost<sup>34</sup> and has also been damaged in other, less apparent ways.<sup>35</sup> Speculation and uncertainty can be costly. HIPAA increases uncertainty through its obscure language and by introducing new, unanswered questions regarding the transmission of health data. Some of those uncertainties include medical malpractice liability, “potential liability under privacy and confidentiality laws, disputes over ownership of health data, and heightened vulnerability to Medicare or Medicaid fraud claims as a result of improved information on the match between services rendered and services billed.”<sup>36</sup>

Moreover, the HIPAA regulations are “so abstruse and intricate—so ‘extensive, vast, and detailed’—that words commonly used to describe them include ‘patchwork,’ ‘erratic,’ and ‘morass.’”<sup>37</sup> There is ongoing debate over how HIPAA impacts hospitals and other health care providers.<sup>38</sup> This uncertainty—inspired by the ambiguous and convoluted language of the regulations themselves, and compounded by the uncertainty inherent when Congress passes broad, behavior-altering regulations—adds to the costs of implementation and delays the adoption of EHRs.

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32. See Catherine M. DesRoches et al., *Small, Nonteaching, and Rural Hospitals Continue to be Slow in Adopting Electronic Health Record Systems*, 31 HEALTH AFF. 1092, 1092 (2012) (“To date, the pace of adoption of EHR systems in US hospitals has been slow, and the future pace of adoption and distribution of adoption across all hospitals remains uncertain.”); Ashish K. Jha, *Meaningful Use of Electronic Health Records: The Road Ahead*, 304 JAMA 1709, 1709–10 (2010); Ashish K. Jha et al., *A Progress Report on Electronic Health Records in U.S. Hospitals*, 29 HEALTH AFF. 1951, 1953 (2010) (finding only “modest gains” in the adoption of EHRs between 2008 and 2009).

33. See Kumar & Aldrich, *supra* note 19, at 311–12.

34. SPENCER, *supra* note 10, at 133 (“[I]t could likely cost the health care provider sector millions of dollars to implement the law requiring an accounting of disclosures from an electronic health record for treatment, payment, and health care operation purposes.”).

35. See Sandeep S. Mangalmurti et al., *Medical Malpractice Liability in the Age of Electronic Health Records*, 36 NEW ENG. J. MED. 2060, 2060 (2010) (“In the excitement over health information technology, some of the potential risks associated with it have received less attention, such as the possible effects of this technology on medical malpractice liability.”).

36. *Id.*

37. Charity Scott, *Is Too Much Privacy Bad for Your Health? An Introduction to the Law, Ethics, and HIPAA Rule on Medical Privacy*, 17 GA. ST. U. L. REV. 481, 481–82 (2001) (internal citations omitted).

38. Compare Brown, *supra* note 5, at 35–36 (describing HIPAA’s requirements as logical changes that are necessary to accommodate patient expectations without discussing the practical impact that the requirements may have on health care providers), with SPENCER, *supra* note 10, at 131–32 (warning that HIPAA’s requirements come with extreme and impractical costs); see also Muller, *supra* note 30, at 33.

More recently, since Congress passed HITECH, HHS has been charged with developing requirements for the “meaningful use” of EHRs.<sup>39</sup> If health care providers show that they use EHRs in meaningful ways by meeting these requirements, their Medicare and Medicaid reimbursements increase.<sup>40</sup> If providers do not meet these requirements within the next two to three years, depending on several variables, then their Medicare and Medicaid reimbursements will instead decrease as a penalty.<sup>41</sup> With these massive incentives, HITECH also increased penalties for privacy violations of the original HIPAA Privacy Rule.<sup>42</sup> Therefore, despite HHS’s lofty and commendable goals to promote the use of EHRs, it has done little to address the confusing nature of HIPAA’s original privacy standards.

If the ambiguous language of the regulations is not enough of a challenge, increased implementation costs and adoption delays are also caused by the uncertainty of rapidly changing technology and the unknown effects EHRs may have on malpractice claims, fraud claims, and data ownership disputes.<sup>43</sup> As technology changes, the regulations do not always keep up, which forces health care providers, and their attorneys, to continue to speculate about the impacts of adopting new and promising technologies.<sup>44</sup> All of this uncertainty leads to speculation and, rather than improving efficiency and decreasing costs as HIPAA was originally intended to do, has only further burdened the dissemination of health information by delaying the progress of health information technology.

## 2. Patient Access to Health Information

Second, HIPAA has also failed to make patients’ own health information available to them. Not only must patients pay to access their own information, the process for obtaining that information is nearly as luddite as it was before the original HIPAA regulations were announced.<sup>45</sup> The process begins with figuring out where a patient might have medical records stored. Because EHRs are not centralized and formats between providers are not compatible, even if a provider

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39. See, e.g., Basis and Purpose, 42 C.F.R. § 495.2 (providing an overview of the regulations HHS has designed to implement HITECH).

40. CTRS. FOR MEDICARE & MEDICAID SERVS., *supra* note 11, at 1.

41. CTRS. FOR MEDICARE & MEDICAID SERVS., AN INTRODUCTION TO THE MEDICARE EHR INCENTIVE PROGRAM FOR ELIGIBLE PROFESSIONALS 16.

42. Corrine P. Parver & Savannah Thompson-Hoffman, *How the American Recovery and Reinvestment Act of 2009 Changed HIPAA’s Privacy Requirements*, CCH HEALTH CARE COMPLIANCE LETTER, Jul. 28, 2009, at 6.

43. Mangalmurti et al., *supra* note 35, at 2060.

44. See Watson A. Bowes, *Assessing Readiness for Meeting Meaningful Use: Identifying Electronic Health Record Functionality and Measuring Levels of Adoption*, AMIA 2010 SYMPOSIUM PROCEEDINGS 66–67 (2010) (evaluating specific shortcomings in current EHR technology when compared to HIPAA’s “meaningful use” requirements); DesRoches et al., *supra* note 32, at 1093 (2012) (categorizing different EHR systems as “comprehensive” or “basic”); Mangalmurti et al., *supra* note 35 at 2060–61.

45. See, e.g., DR. HUMAIRA A. SIDDIQI, MD, *New Patient Forms*, [http://www.drhsiddiqi.com/uploads/New\\_Patient\\_Forms.pdf](http://www.drhsiddiqi.com/uploads/New_Patient_Forms.pdf) (forms and instructions for requesting medical records by mail and requiring a signed agreement that the patient will pay any necessary costs for obtaining medical records).

has adopted EHRs at all, those records will likely not contain the same information as those stored by the patient's other health care providers.<sup>46</sup> Once the patient has a list of all the possible physical locations for his or her records, the patient can then request the records. Unfortunately, that request is rarely just a mouse click away. The patient must generally go into the office where the records are stored and fill out a form or bring in a letter requesting the appropriate records.<sup>47</sup> Or, in more tech-savvy offices, a fax might be acceptable.<sup>48</sup>

Then the patient waits. Whenever the office has the time to process the request, if it decides not to decline it altogether, it will begin printing out the dozens, if not hundreds of pages from the patient's file.<sup>49</sup> The office may then charge for all of the paper, ink, and time it just spent on the patient's behalf before handing over the nonelectronic file.<sup>50</sup> Presumably, this process is not due to the health care provider's love of long and tedious processes. Rather, it is due to the fact that technologies, and the companies that sell the HIT to providers, have not advanced fast enough to satisfy HIPAA's standards.<sup>51</sup> While HIPAA contemplates that everyone should be able to access their health information electronically for a minimal fee,<sup>52</sup> EHR systems have not been widely adopted; and even where they are, many systems in use today do not yet have the capability to share secure files electronically.<sup>53</sup>

### 3. Protecting Patient Privacy

Finally, despite all of its failings, has HIPAA at least protected the privacy of health care consumers? Has it successfully put those consumers' minds at ease and inspired confidence in EHRs? The answer, while not resounding, seems to be no. Various studies and scholarly articles attack HIPAA for being too lenient when it comes to the danger that a health care provider might violate a

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46. See Julie Appleby, *Five Lessons from Seattle on Adopting Electronic Medical Records*, KAISER HEALTH NEWS (Aug. 10, 2009), <http://www.kaiserhealthnews.org/stories/2009/august/10/seattle-health-info-tech.aspx> (despite hospitals sitting within blocks from one another and using state-of-the-art EMR systems, "a patient crossing the street from one hospital to another would be wise to bring paper records: The systems, made by different manufacturers, can't talk to each other").

47. See *Your Medical Record Rights*, GEORGETOWN UNIV. HEALTH POLICY INST., <http://hpi.georgetown.edu/privacy/records.html> (last visited Oct. 2, 2013) (providing detailed instructions for what a patient can and cannot do in order to access patients' health information in each state).

48. See *id.*

49. See *id.*

50. See *id.*

51. See Bowes, *supra* note 44, at 66–67.

52. 42 U.S.C. § 17935(e) (2012).

53. See Bowes, *supra* note 44, at 66–67 (evaluating the shortcomings of modern EHR systems); *but see, e.g.*, Charlene Johnson & Deborah E. Swain, *Managing Your Medical Data*, 38 BULL. AM. SOC'Y FOR INFO. SCI. & TECH. 64, 65 (2012) (describing how veterans can access their health records electronically through My HealtheVet).

patient's privacy.<sup>54</sup> Others worry that HIPAA stifles the flow of valuable information to the detriment of both technological progress and patients' health.<sup>55</sup> And a few are dismissive of HIPAA's privacy implications entirely.<sup>56</sup> From any angle, there is little evidence that Congress's focus on consent, control, and restrictions has encouraged trust or confidence in information technology and EHR systems.

Of all of the goals, primary and secondary, of national health information privacy regulation, few have been realized. Although HIPAA was only recently amended by HITECH, it seems unlikely that widespread adoption of EHRs will occur by HITECH's 2014 deadline. When few argue that these goals are not worth pursuing, and Congress has approved large subsidies to help health care providers pay for new EHR systems, what is preventing the free flow of health information? Primarily, that flow is stifled by uncertainty of health care consumers and providers alike.

## II. GOING FORWARD: WHAT WE SHOULD ACCOMPLISH

Going back to our original protagonist: Bob has no trust in the system. Bob has no reason to. Unlike his beloved ice cream, Bob cannot calorie check his medical records at a glance. Unlike the store hours or a taxicab phone number, he cannot access his information online or readily find out where his information has been sent or why.<sup>57</sup> Bob is pretty sure that it would have been nice if the hospital

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54. See, e.g., McGraw et al., *supra* note 28, at 421–23 (recommending tougher consent requirements, stronger privacy rules, and more stringent limitations on access to health information as a means to improve consumer trust in HIT).

55. See, e.g., Meredith Kapushion, *Hungry, Hungry HIPAA: When Privacy Regulations Go Too Far*, 31 *FORDHAM URB. L.J.* 1483, 1488–91 (2003) (evaluating the economic value of privacy compared to the social benefits of “relaxed privacy standards”); Jane Yakowitz Bambauer, *Death by HIPAA*, *HUFFINGTON POST* (June 25, 2012, 5:15 p.m.), [http://www.huffingtonpost.com/jane-yakowitz-bambauer/death-by-hipaa\\_b\\_1619318.html](http://www.huffingtonpost.com/jane-yakowitz-bambauer/death-by-hipaa_b_1619318.html) (considering how HIPAA may have restricted information that would have prevented deaths from Vioxx, an arthritis drug).

56. See, e.g., William H. Frist, *Health Care in the 21st Century*, 352 *NEW ENG. J. MED.* 267 (2005) (describing the ideal uses and possibilities for HIT without regard for the challenges that protecting privacy under such ideal conditions would pose); Carleen Hawn, *Take Two Aspirin and Tweet Me in the Morning: How Twitter, Facebook, and Other Social Media are Reshaping Health Care*, 28 *HEALTH AFF.* 361, 366 (2009) (treating HIPAA's privacy standards as a mere hurdle to circumvent by using private patient portals rather than public social media services to transmit health care information).

57. Although some companies have attempted to provide online access to health records, the reliability of the health information accumulated by those services, while subject to current restrictions, has proven questionable at best. See Lisa Wangsness, *Electronic Health Records Raise Doubt: Google Service's Inaccuracies May Hold Wide Lesson*, *BOS. GLOBE* (Apr. 13, 2009), [http://www.boston.com/news/nation/washington/articles/2009/04/13/electronic\\_health\\_records\\_raise\\_doubt/](http://www.boston.com/news/nation/washington/articles/2009/04/13/electronic_health_records_raise_doubt/). Some of those services have since shut down entirely. *An Update on Google Health and Google PowerMeter*, *GOOGLE* (June 24, 2011), <http://googleblog.blogspot.com/2011/06/update-on-google-health-and-google.html>. Others, although they remain available, have very limited capabilities. The options they provide consumers with for compiling health data, for example, are

emergency department could have automatically known his medical history and drug allergies when he arrived. He is also pretty sure that his primary care physician would like to know what notes the emergency staff took about his condition before his next appointment. But Bob is still nervous about this health care information.

Proponents for Bob's paranoid state believe that he will no longer be nervous as soon as the privacy regulations are strong enough to adequately protect him.<sup>58</sup> Bob would be better served, however, by recognizing that sometimes familiarity and understanding are more likely to breed trust than opposition and protectionism.<sup>59</sup> In the end, Bob may actually be better served by less restrictive privacy policies that prioritize the free flow of information than by policies that strive to protect personal privacy by sacrificing the accuracy and completeness of important medical information.<sup>60</sup>

The use of transparency and disclosures to encourage trust and confidence is not a new concept. Other areas, such as the food industry, financial investments, and environmental regulations, have focused on disclosures and transparency for years.<sup>61</sup> By using a similar model and applying it to information technology, regulators can evaluate the breadth and uncertainty that the term "privacy" connotes by viewing privacy concerns through the lens of transparency rather than restriction.<sup>62</sup>

#### *A. Transparency Defined: Interactivity and Disclosures*

Transparency is:

[T]he extent to which an individual exhibits a pattern of openness and clarity . . . toward others by sharing the information needed to make decisions, accepting others' inputs, and disclosing his/her personal values, motives, and sentiments in a manner that enables

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hardly automated or simple. See, e.g., PHELPS CNTY. MED. CNTR., *Patients Deserve Access over Their Medical Records*, <http://www.pcrmc.com/healthvault/health-information.aspx> (last visited Nov. 7, 2013) ("There are a number of ways to get your health information into HealthVault[]. You can type it in yourself, upload documents and medical images, have your doctor fax records directly to HealthVault[], or use a service to collect your records and turn them into digital information.").

58. See McGraw et al., *supra* note 28, at 417–18.

59. See Johnson & Swain, *supra* note 53, at 65 (describing how the use of explanations, information, training, and virtual tours encourages trust and understanding).

60. See MARY GRAHAM, *DEMOCRACY BY DISCLOSURE* 20 (2002) (accuracy); Naren Ramakrishnan, David A. Hanauer & Benjamin J. Keller, *Mining Electronic Health Records*, 43 *COMPUTER* 95, 96–97 (2010) (completeness).

61. GRAHAM, *supra* note 60, at 2–3.

62. See Fred H. Cate, *Principles for Protecting Privacy*, 22 *CATO J.* 33, 34–36 (2002).

followers to more accurately assess the competence and morality of the leader's actions.<sup>63</sup>

In health care, the leaders are the doctors, and the followers are the patients who seek the information they need to evaluate their own health care decisions.

Practically speaking, transparency can be promoted through two systems: interactivity and disclosures. Most current legislative implementations of transparency have focused on disclosures, while less formal, social implementations of transparency focus on interactivity. In either system, transparency is only effective if the transparent information is also accessible.

In several other areas of the law, transparency has been used as a remedial measure to promote social welfare.<sup>64</sup> Transparency in those areas has been achieved, to a large degree, through disclosures. "Just as investors have long compared companies' earnings, travelers can compare airline safety records, shoppers can compare the healthfulness of cereals and canned soups, and community residents can compare toxic releases from nearby factories."<sup>65</sup> In these contexts—finance, food and drug safety, and environmental protection—disclosures are the name of the game when it comes to ensuring social well-being.<sup>66</sup>

Critics of these types of regulatory disclosures point out that government-mandated disclosures do not put information into the hands of consumers.<sup>67</sup> Rather, the regulations merely create a requirement that companies disclose information to the government, where it silently remains for indefinite periods of time.<sup>68</sup> They also argue that it may be illogical for the legislature to force companies to disclose information while shying away from asking whether companies should have access to, or collections of, consumer's personal information in the first place.<sup>69</sup>

These critiques, however, only apply when the flow of information toward a regulated company is, or perhaps should be, restricted.<sup>70</sup> Health care providers, as a specific type of regulated company, have very few restrictions on what information they can collect about individuals. This distinction is fairly logical. Health care providers cannot care for consumers if they do not know certain past or present medical information about each individual consumer. In

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63. Steven M. Norman, Bruce J. Avolio & Fred Luthans, *The Impact of Positivity and Transparency on Trust in Leaders and Their Perceived Effectiveness*, 21 LEADERSHIP Q. 350, 352 (2010).

64. See GRAHAM, *supra* note 60, at 2–3 (discussing the effects of transparency on the financial industry, food and drug safety, and environmental protection regulations).

65. *Id.* at 3.

66. *See id.*

67. *Id.* at 4.

68. *See id.* ("In principle, the public has a right to much of the information . . . [that] inform[s] these mandates. But in practice, most of it has made a one-way trip to Washington or state capitals, where it has remained scattered in government files.").

69. *See id.* at 3–4.

70. *See id.* at 20.

other words, we do not need to protect patient information from health care providers themselves when providers are collecting and using that information for its intended treatment purposes.

What individual consumers do need, however, is access to information about how their information is being used. The benefits of health information come not only from sharing it with health care providers for treatment of each individual patient, but also from sharing that information with third parties such as researchers—a transaction that some patients may not be comfortable with, and all patients would want to be able to know about. Individual consumers, however, currently have very limited access to information about what is happening with their information.<sup>71</sup> Transparency in health care can therefore be promoted by disclosures that focus on this underserved need to lend consumers insight into what goes on behind the scenes with their health information.

On the informal side, transparency is also promoted by interactivity and familiarity. Users who are more familiar and more comfortable with technology, such as internet websites, are more likely to be satisfied with the reliability of information available online.<sup>72</sup> Those same users desire more interactivity with that information.<sup>73</sup> Although interactivity and transparency may be thought of as two distinct subjects, true transparency does not exist until the information flows both ways. Transparency, and therefore trust, will improve substantially when users like Bob not only access their own information and know where it is being sent, but when they can also submit notes and concerns about the content and use of their information.<sup>74</sup>

Finally, transparency is useless unless the information it provides is accessible, physically and intellectually, to those who seek to understand it.<sup>75</sup> In a

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71. Georgetown University has put together consumer guides that give patients a quick summary of what rights they may or may not have in any particular state. *See, e.g.*, JOY PRITTS & NINA L. KUDSZUS, GEORGETOWN UNIV. HEALTH POLICY INST., *YOUR MEDICAL RECORD RIGHTS IN ARIZONA (A GUIDE TO CONSUMER RIGHTS UNDER HIPAA)* (2005) (explaining the formats health providers might use to transmit records, examining what fees providers may charge patients for copies of their records, and describing other limitations that may apply to information requests).

72. Eric W. Welch & Charles C. Hinnant, *Internet Use, Transparency, and Interactivity Effects on Trust in Government*, in *PROCEEDINGS OF THE 36TH HAWAII INTERNATIONAL CONFERENCE ON SYSTEM SCIENCES* 2–3 (2003).

73. *Id.* at 3.

74. HHS has begun to recognize this need. Through its meaningful use incentive program, HHS has established broad goals that focus on patients' access to, and interactivity with, their own health information. *Meaningful Use Definition & Objectives*, HEALTHIT.GOV, <http://www.healthit.gov/providers-professionals/meaningful-use-definition-objectives> (last visited Oct. 19, 2013). HHS's meaningful use goals include engaging patients, increasing transparency and efficiency, and empowering individuals. Those results, however, are to be accomplished by "maintain[ing] privacy and security of patient health information." *Id.*

75. Henriette Cramer et al., *The Effects of Transparency on Trust in and Acceptance of a Content-Based Art Recommender*, 18 *USER MODELING & USER-ADAPTED INTERACTION* 455, 466 (2008); GRAHAM, *supra* note 60, at 3.

study from 2001, researchers found that during any given health-related internet search based on a specific medical issue, only 20% of English-language results on the first page of the search results were relevant, only 45% were completely accurate, and 24% did not discuss the specific medical issue that the user searched for at all.<sup>76</sup> The study also found that all of these internet sites required a high-school or greater reading ability.<sup>77</sup>

As a whole, transparency must therefore be established through disclosures targeted at providing consumers with information about how their medical data is used, by improving interactivity and familiarity with consumers' own medical data, and by ensuring that all forms of communication between health care providers and consumers are both as physically and intellectually accessible as possible.

### *B. Why Transparency Improves Trust*

In any context, trust is “an elusive concept.”<sup>78</sup> In an attempt to capture the idea of trust, some scholars have drawn it into three general categories: fiduciary trust, mutual trust, and social trust.<sup>79</sup> “These different concepts of trust interact such that mutual trust contributes to social trust, and social trust provides the context within which individuals can establish mutual trust and maintain fiduciary trust.”<sup>80</sup>

Fiduciary trust is based on principle-agent theory.<sup>81</sup> The relationship between doctor and patient is, to a notable extent, a fiduciary relationship.<sup>82</sup>

76. Gretchen A. Berland et al., *Health Information on the Internet: Accessibility, Quality, and Readability in English and Spanish*, 285 JAMA 2612, 2612 (2001).

77. *Id.* Another study, from 2008, found that out of 100 health-related articles published online, 75–96% were above a ninth-grade reading level, with the highest required reading levels ranging from grade 18 to grade 22 even though “the typical American reads between a 7th and 8th grade level.” Tiffany M. Walsh & Teresa A. Volsko, *Readability Assessment of Internet-Based Consumer Health Information*, 53 RESPIRATORY CARE 1310, 1311–12 (2008).

78. Henk Akkermans, Paul Bogerd & Jan van Doremalen, *Travail, Transparency and Trust: A Case Study of Computer-Supported Collaborative Supply Chain Planning in High-tech Electronics*, 153 EUR. J. OF OPERATIONAL RES. 445, 447 (2004). For a detailed look at the importance of trust in the health provider context, and arguments for and against different definitions of trust, see generally Robert Gatter, *Faith, Confidence and Health Care: Fostering Trust in Medicine Through Law*, 39 WAKE FOREST L. REV. 395 (2004); Mark A. Hall, *Caring, Curing, and Trust: A Response to Gatter*, 39 WAKE FOREST L. REV. 447 (2004); and Mark A. Hall, *Trust in Physicians and Medical Institutions: What Is It, Can It Be Measured, and Does It Matter?*, 79 MILBANK Q. 613 (2001).

79. Welch & Hinnant, *supra* note 72, at 1.

80. *Id.* at 2.

81. *Id.*

82. Although the doctor-patient relationship is similar to a fiduciary relationship, and is often described as a fiduciary relationship, it may not be treated as a fiduciary relationship in every context. See *Lockett v. Goodill*, 430 P.2d 589, 591 (Wash. 1967) (“The relationship of patient and physician is a fiduciary one of the highest degree. It involves every element of trust, confidence and good faith.”); Marc A. Rodwin, *Strains on the*



Doctors have specialized knowledge in their field and the authority and control to use that knowledge in a way that, ethically, must benefit their patients.<sup>83</sup> Patients, meanwhile, rely on doctors to help them make decisions and are dependent upon their doctors for information, authorization, and care.<sup>84</sup> This fiduciary-like relationship is maintained by mutual and social trust.<sup>85</sup>

Mutual trust develops when individuals who repeatedly interact become more familiar with one another. As individuals continue their social exchanges over time, they better understand each other.<sup>86</sup> This phenomenon is sometimes labeled habituation: “[I]t is repeated interaction which leads to the forming of habits and the institutionalisation of behaviour. Any human activity that is frequently repeated is subject to habituation, which frees the individual from having to make decisions and thus provides psychological relief.”<sup>87</sup> Habituation, however, is only the beginning of trust. Mutual trust is also defined as a willingness to be vulnerable in a relationship due to expectations that the other person will act consistently, positively, and dependably.<sup>88</sup> Trust in individual relationships can further be defined as a feeling derived from perceptions of ability, competence, performance, integrity, and benevolence.<sup>89</sup> When patients regularly visit their health care providers and those providers exhibit these trust-forming attributes, mutual trust develops between the parties.

Mutual trust then creates social trust: trust that extends, beyond individual relationships, to groups of individuals and institutions.<sup>90</sup> These groups and institutions may include a government, a business, or a hospital. If trust in our health care system begins with mutual trust, the question then becomes: How can we encourage mutual trust in the health care context? Mutual trust can be encouraged through transparency.

Transparency and trust are intricately and inseparably interlaced.<sup>91</sup> Even outside of the health or medical context, trust in online data is greatly impacted by transparency. Users of Wikipedia, for example, are more trusting of authors that

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*Fiduciary Metaphor: Divided Physician Loyalties and Obligations in a Changing Health Care System*, 21 AM. J.L. & MED. 241, 245 (1995) (“Certain features of patient-physician relations closely resemble classic fiduciary relationships.”); *but see* Joseph M. Healey, Jr. & Kara L. Dowling, *Controlling Conflicts of Interest in the Doctor-Patient Relationship: Lessons from Moore v. Regents of the University of California*, 42 MERCER L. REV. 989, 1001 (1991) (“Though it is frequently claimed that the doctor-patient relationship is a fiduciary relationship, such claims are often made without substantial explanation or justification or without acknowledging the full consequences of such a characterization.”).

83. Rodwin, *supra* note 82, at 245–46.

84. *Id.*

85. *See* Welch & Hinnant, *supra* note 72, at 2.

86. Akkermans, Bogerd & van Doremalen, *supra* note 78, at 448.

87. *Id.*

88. Norman, Avolio & Luthans, *supra* note 63, at 351.

89. *Id.*

90. *See* Akkermans, Bogerd & van Doremalen, *supra* note 78, at 449; Welch & Hinnant, *supra* note 72, at 2.

91. *See* Akkermans, Bogerd & van Doremalen, *supra* note 78, at 447.

transparently list their articles' sources.<sup>92</sup> Software that recommends music and art to users is seen as more trustworthy, and its outcomes are more readily accepted, when users have insight into how the recommendation system works.<sup>93</sup> In the organizational-leadership context, “[o]pen communication or communication transparency has historically been viewed as an essential ingredient in effective organizations.”<sup>94</sup> Not only does transparency in organizations improve trust, but it also improves “honesty, effective listening, . . . supportiveness, and frankness”<sup>95</sup>—all vital elements of an effective doctor–patient relationship.

Applying these concepts to health care providers, transparency through traditional doctor–patient relationships, combined with modern health technology, can improve overall trust in our health care system.<sup>96</sup> Health care providers, traditionally, have thrived on trusting, personal relationships with patients.<sup>97</sup> Those relationships, based on mutual trust, support social trust in hospitals as institutions and enhance fiduciary trust when doctors help patients with their health care decisions.

Health *technology*, however, does not survive the same analysis. Patients do not know what notes their doctors have taken during a given appointment.<sup>98</sup> They do not know where those notes were sent or what will become of them. Although patients may have a good, trusting relationship with their doctors, they often have no relationship, whether mutual, social, fiduciary, or otherwise, with their own health records.<sup>99</sup> Trust in those records must therefore come from transparency.

Health care providers that improve transparency could improve honesty, supportiveness, and open communication between doctors and patients overall. As technology expands and health care becomes more intertwined with technology, HIT systems will instill more trust as they adopt the same qualities that inspire

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92. Bongwon Suh et al., *Lifting the Veil: Improving Accountability and Social Transparency in Wikipedia with WikiDashboard*, in CHI '08 PROCEEDINGS OF THE SIGCHI CONFERENCE ON HUMAN FACTORS IN COMPUTING SYSTEMS 1037 (2008).

93. See Cramer et al., *supra* note 75, at 466–67.

94. Norman, Avolio & Luthans, *supra* note 63, at 352.

95. *Id.*

96. See Delbanco, *supra* note 23, at 466 (“Among the 73 out of 104 PCPs (70%) who responded with free text to the question, ‘What was the best thing about opening your notes to patients online?’, doctors most frequently commented about strengthened relationships with some of their patients including enhanced trust, transparency, communication, and shared decision making.”) (internal parenthetical references omitted).

97. See *Lockett v. Goodill*, 430 P.2d 589, 591 (Wash. 1967).

98. See *A Shareable HIPAA Clarification Flyer: Teaching HIPAA with a Seinfeld Clip*, E-PATIENTDAVE.COM (Apr. 23, 2010), <http://epatientdave.com/2010/04/23/elaine-and-kramer-play-gimme-my-damn-data/>.

99. Some patients may, on the other hand, know the content of their medical records because HIPAA does require that health care providers allow patients to access their own files. *Id.* This access, however, is often misunderstood by both patients and health care providers, and is therefore used infrequently. *Id.*

trust in doctors. Like individual relationships with doctors, access to health information needs to be competent, dependable, able, positive, and transparent.

### *C. Transparency in Health Records: What Makes Health Records Different*

While the need for transparency in medical information is very similar to the need for transparency in food and drug contents, financial risks, and pollution statistics, medical information has its own specific needs for transparency. Medical data is different from other types of data.<sup>100</sup> Special concerns for health information include problems with health data portability, the number of diverse types of health data that exist, and medical ethics. But there are also benefits that are unique to medical data. Those benefits include the intellectual frameworks and physical infrastructure that health care providers have already widely adopted, as well as the inherent consumer popularity that comes with granting access to online information.

#### *1. Uniqueness of Health Data: The Challenges*

Data portability, the ability of data to transfer between different mediums, has several obstacles to overcome. Health data, specifically, presents several of its own problems with data portability. Unobstructed data portability, although extremely desirable and convenient,<sup>101</sup> raises concerns over compatibility, costs, competition, and, of course, privacy.<sup>102</sup>

With health care data, and EMRs specifically, very little has been achieved in terms of portability.<sup>103</sup> Even though the federal government, for example, has created comprehensive HIT systems for both the Department of Defense and for Veterans Affairs, medical records from these two systems are not yet transferrable from one to the other.<sup>104</sup> Scholars who have attempted to

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100. See generally Krzysztof J. Cios & G. William Moore, *Uniqueness of Medical Data Mining*, 26 ARTIFICIAL INTELLIGENCE IN MED. 1 (2002) (discussing the specific legal and ethical concerns raised by the proliferation of medical data mining in contrast with the concerns raised by other types of data mining).

101. Peter Swire & Yianni Lagos, *Why the Right to Data Portability Likely Reduces Consumer Welfare: Antitrust and Privacy Critique*, 72 MD. L. REV. 335, 336–37 (2013).

102. See generally *id.*; Terry, *supra* note 12.

103. David A. Hyman, *HIPAA and Health Care Fraud: An Empirical Perspective*, 22 CATO J. 151, 151 (2002) (“The portability provisions [of HIPAA] have had relatively little impact on the portability of health care benefits.”); see generally SHEERA ROSENFELD ET AL., *AVALERE, INTEROPERABILITY AND MEANINGFUL USE / KEYS TO THE FUTURE OF HEALTH INFORMATION EXCHANGE 3* (2009) (defining interoperability as the ability for different HIT systems to communicate with one another and discussing the challenges of accomplishing that goal nationally).

104. See PETER G. GOLDSCHMIDT, *COMM. OF THE ACM, HIT AND MIS: IMPLICATIONS OF HEALTH INFORMATION TECHNOLOGY AND MEDICAL INFORMATION SYSTEMS* 70 (OCT. 2005).

standardize EMRs in Europe have experienced similar difficulties.<sup>105</sup> These challenges stem from technical complications revolving around medical records' heterogeneity.<sup>106</sup>

Heterogeneity in medical records refers to the diversity of types of medical records, the ways that medical data can be presented and interpreted, and concerns over subjectivity and margins of error.<sup>107</sup> These variations are necessary to "accommodate the individuality of the clinician as well as the patient"<sup>108</sup> and must therefore be accurately preserved to protect patients' health and safety. Examples of different types of medical data formats include "various images, interviews with the patient, and physician's notes . . . ."<sup>109</sup> And together, these various pieces of data paint a picture of a patient that is only accurate if the context of the patient's records is also preserved to account for doctors' interpretations, estimates, and reasoning surrounding various medical decisions.<sup>110</sup> For these reasons, it is essential to standardize EMRs in ways that will maintain context and clarity between different systems and providers.

While compatibility, privacy, and cost concerns are therefore very real in the health care context, competition concerns also present their own, health-care-specific problems. Competition between social networking companies,<sup>111</sup> for example, could be considered a healthy part of the free market; allowing companies to resist compatibility of data between companies, as a means of competition, could therefore be beneficial to that free market model.<sup>112</sup> Companies that develop EMR systems, however, also resist compatibility to "emphasize their uniqueness to gain market share."<sup>113</sup> Because of that resistance, although there is some anticipation that compatibility and national portability might eventually become a reality,<sup>114</sup> progress towards national EMR portability has been extremely slow.<sup>115</sup>

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105. Dipak Kalra, *Electronic Health Record Standards, in* INT'L MED. INFORMATICS ASS'N, IMIA YEARBOOK OF MEDICAL INFORMATICS 136, 136 (2006) ("Parts of the challenge of EHR interoperability cannot yet be standardised [sic], because good solutions to the preservation of clinical meaning across heterogeneous systems remain to be explored.").

106. Cios & Moore, *supra* note 100, at 2; Kalra, *supra* note 105, at 136.

107. *See* Cios & Moore, *supra* note 100, at 2–8.

108. Kalra, *supra* note 105, at 137.

109. Cios & Moore, *supra* note 100, at 2.

110. *Id.* at 2–3.

111. *See generally* Swire & Lagos, *supra* note 101 (discussing how widespread data portability between social media outlets could reduce competition between services and innovation in social media technology).

112. *Id.*

113. Appleby, *supra* note 46.

114. *See* Tracey L. Murray, Mona Calhoun & Nayna C. Philipsen, *Privacy, Confidentiality, HIPAA, and HITECH: Implications for the Health Care Practitioner*, 7 J. OF NURSE PRACTITIONERS 747, 750 (2011) ("[I]t is not certain that the systems will be compatible with other external systems.").

115. *See supra* Part I.B.

Manipulating medical data, unlike other types of data, also implicates special ethical concerns. Most worrying is the definite possibility that, if you do it wrong, “it will kill people.”<sup>116</sup> Beyond fear of misdiagnosis, drug conflicts, and misinterpretation of medical records, however, are also ethical fears over who owns a patient’s medical data, what potential liability might be associated with EMRs, and how the concept of doctor–patient confidentiality impacts the dissemination of electronic medical information.<sup>117</sup> All of this ethical uncertainty counteracts the goals of improving the information flow. Uncertainty raises costs and slows the adoption of new technologies.<sup>118</sup>

## 2. Uniqueness of Health Data: The Benefits

Despite concerns over ethics, portability, and heterogeneity, the use of transparent medical records also has profound benefits. Studies have shown that electronic medical records can be extremely beneficial in terms of both health outcomes and patients’ finances.<sup>119</sup> Unlike data in almost any other context, medical data is directly and inseparably linked to personal health.<sup>120</sup> And beyond cost savings, or even personal health, studies have shown that the implementation of portable and accessible medical record systems that allow patients to readily read and interact with their own records is extremely popular with both patients and physicians.<sup>121</sup> The potential health and social benefits of health data may also extend beyond the doctor–patient relationship when third parties are allowed to access certain health information to conduct research.<sup>122</sup>

Related to patient and consumer trust, transparent access to patients’ own information allows patients to take a more active role in their own health care,<sup>123</sup> and may also indirectly improve patient health as a type of placebo effect.<sup>124</sup>

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116. Appleby, *supra* note 46.

117. Cios & Moore, *supra* note 100, at 8–11.

118. See *supra* Part I.B.1.

119. See *supra* Part II.A.

120. See *id.*

121. Delbanco, *supra* note 23, at 465 (“Nearly 99% of patient respondents at BIDMC, GHS, and HMC wanted continued access to their visit notes, and 86% at BIDMC, 87% at GHS, and 89% at HMC agreed that open notes would be a somewhat or very important factor in choosing a future doctor or health plan.”); see also Gold, *supra* note 23.

122. See generally Charles Safran et al., *Toward a National Framework for the Secondary Use of Health Data: An American Medical Informatics Association White Paper*, 14 J. AM. MED. INFORMATICS ASSOC. 1 (2007).

123. See generally Elizabeth Murray et al., *The Impact of Health Information on the Internet on Health Care and the Physician–Patient Relationship: National U.S. Survey Among 1,050 U.S. Physicians*, 5 J. MED. INTERNET RES. (2003).

124. See Daniel E. Moerman & Wayne B. Jonas, *Deconstructing the Placebo Effect and Finding the Meaning Response*, 136 ANN. INTERNAL MED. 471, 473 (2002) (“The physician’s costume (the white coat with stethoscope hanging out of the pocket), manner (enthusiastic or not), style (therapeutic or experimental), and language are all meaningful and can be shown to affect the outcome . . . .”); Chris van Weel, *Examination of Context of Medicine*, 357 LANCET 733, 733 (2001) (“Since the doctor–patient interaction is part of the

Implementing new technologies to promote access to health information, for example, is a very popular concept. The use of online health advice through web-based services such as WebMD continues to grow.<sup>125</sup> Even so, information sitting alone on the internet and waiting to be snatched up may not be as effective, or as popular, as information presented through a health care provider's more personal touch. Health providers might, for example, provide interactive e-mail counseling, individualized online support, or customized group chat rooms.<sup>126</sup> Allowing patients to access information that is tailored to their own specific needs, and that health care providers can communicate through, can create a whole new level of online health information access in which patients have shown a strong and growing interest.

Advocates of stronger privacy protections and greater restrictions on health information argue that, as patients become more involved in their own health care, their newfound empowerment and self-reliance may add tension to the doctor-patient relationship.<sup>127</sup> It is clear, however, that confidence and trust in the health care system can thrive through the use of online health care access. In one study, patients and physicians alike cited benefits, including "an increased sense of control, greater understanding of their medical issues, improved recall of [patients'] plans for care, better preparation for future visits and an increased likelihood that patients will take their medications as prescribed."<sup>128</sup>

Fortunately, despite the many challenges of implementing HIT systems, the nature of health information also has some inherent advantages over other types of information when it comes to creating a national information system. Specifically, medical needs are a national, and even international, challenge that

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overall context of medical care, the effects of the relationship on the course of illness indicates that the context of care influences patients' well-being.").

125. James G. Anderson, Michelle R. Rainey & Gunther Eysenbach, *The Impact of CyberHealthcare on the Physician-Patient Relationship*, 27 J. MED. SYS. 67, 68 (2003) ("It is estimated that 70 million Americans have used the Internet to acquire knowledge about diseases and treatments, to learn about and enroll in clinical trials, to join support groups, and to obtain other health-related information.").

126. See Viola Spek et al., *Internet-Based Cognitive Behaviour Therapy for Symptoms of Depression and Anxiety: A Meta-Analysis*, 37 PSYCHOL. MED. 319, 327 (2006) (finding a much larger effect on groups of a study where there was individual therapist support in addition to the online support program); Deborah F. Tate, Elizabeth H. Jackvony & Rena R. Wing, *Effects of Internet Behavioral Counseling on Weight Loss in Adults at Risk for Type 2 Diabetes: A Randomized Trial*, 289 JAMA 1833, 1833 (2003) (studying improved weight-loss outcomes for patients who participated in both online weight loss intervention programs and received e-mail counseling); see also Andrew J. Winzelberg et al., *Evaluation of an Internet Support Group for Women with Primary Breast Cancer*, 95 CANCER 1164, 1164 (2003) ("Women who participate in breast cancer support groups have reported significant reduction in their psychologic distress and pain and improvement in the quality of their lives. . . . [A] web-based support group can be useful in reducing depression and cancer-related trauma, as well as perceived stress, among women with primary breast carcinoma.").

127. Anderson, Rainey & Eysenbach, *supra* note 125, at 75-78.

128. Delbanco, *supra* note 23, at 467.

lends itself well to a national system of communication. Despite our many differences, all of humanity suffers common ailments and enjoys common cures. These commonalities make it easier to create a universal vocabulary that can span across all types of health care providers. Furthermore, a great deal of the medical world is already standardized, and commentators in various medical fields recognize how important defining key terms clearly and consistently can be when standardizing the nomenclature has not been effective.<sup>129</sup>

Finally, there is already a great deal of infrastructure in place to make advances in HIT possible. Hospitals and other health care providers are planning, or have already begun, to implement HIT due to the huge financial incentives that HITECH provides.<sup>130</sup> Basic technology that can be upgraded as new software develops, such as computers, scanners, internet access, and secure servers are often already in place.

With health records, the stakes are high. There are extreme risks of careless implementation, and there is a great deal of uncertainty in ethical obligations. But the rewards—patient trust, familiarity, and quality of care that all work together to improve patient outcomes and to lower health care costs—are at least as high as the risks. Because of these stakes, the half-handed approach Congress took when it implemented HIPAA and the HIPAA Privacy Rule must be starkly revised to explicitly focus on the above factors that truly matter when it comes to the success of a national EMR system.

### III. HOW TO MOVE FORWARD: CHANGING PERSPECTIVES ON HEALTH INFORMATION AND PRIVACY

HHS's current philosophy for implementing HITECH is a small step in the right direction. HHS has begun to focus intently on the benefits of HIT and the best, most effective ways to encourage the use of HIT.<sup>131</sup> While HHS continues to focus on use, availability, and patients' control over their own health care, however, it has overlooked the benefits of transparency in the system of information itself.

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129. See Johan T. den Dunnen & Mark H. Paalman, *Standardizing Mutation Nomenclature: Why Bother?*, 22 HUMAN MUTATION 181, 181–82 (2003) (discussing the hazards of failing to strictly adhere to labeling standards for genetic mutations); Peter Ferenci et al., *Hepatic Encephalopathy—Definition, Nomenclature, Diagnosis, and Quantification: Final Report of the Working Party at the 11th World Congress of Gastroenterology, Vienna, 1998*, 35 HEPATOLOGY 717 (2002) (describing how standardizing nomenclature related to hepatic encephalopathy would “normalize the performance of clinical studies and therapeutic trials in HE”).

130. Terry, *supra* note 12, at 118 (“Already, 81 percent of hospitals and 41 percent of office physicians are saying they intend to achieve meaningful use of EHRs and qualify for Medicare and Medicaid incentive payments.”).

131. See, e.g., John Halamka et al., *Health Information Exchange and Interoperability: Sharing Information to Improve Patient Care*, ONC ANNUAL MEETING 2012 (Dec. 12, 2012), <http://www.healthit.gov/oncmeeting/webcast/>; Lygeia Riccardi & Dan Kraft, Address at the ONC Annual Meeting (Dec. 12, 2012).

A panel assembled to tackle the challenges presented by the widespread use, particularly secondary use, of health care data strongly recommended that future regulations focus on working to “increase transparency of data use and promote public awareness.”<sup>132</sup> Although HHS is promoting doctors’ use of health data and modern technologies, it has failed to let go of misleading, confusing past attempts to regulate the use of data through HIPAA. HHS has not proposed any national solutions to health data interoperability issues,<sup>133</sup> and it has not improved consumer awareness.

By diminishing its focus on information privacy and focusing on several key issues related to the transparency of data collection, HHS could reduce uncertainty and speed up the adoption of EMRs and other beneficial HITs.

#### *A. The Misplaced Focus on Privacy*

If transparency and information are so crucial, then what are we waiting for? Was there really a reason to worry about privacy when HIPAA was first enacted? Many valid reasons to worry about who can access an individual’s health information did, and still do, exist. Those concerns include social dynamics, employment status, and health insurance.<sup>134</sup> These concerns, however, do not warrant the broad-reaching chokehold that Congress placed on the dissemination of almost all health information.

Employment concerns are based in two main areas: discrimination and costs in the form of insurance.<sup>135</sup> Employers discriminate based on mental illness<sup>136</sup> and stigmatize physical diseases such as AIDS.<sup>137</sup> Insurance costs for employers can fluctuate based on genetics<sup>138</sup> and gender.<sup>139</sup> Many of these areas of discrimination, however, are already protected by other federal statutes, such as the

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132. Safran et al., *supra* note 122, at 2.

133. Terry, *supra* note 12, at 119 (fearing that “without insisting on interoperability through MU there is the danger of replacing paper silos with electronic ones”).

134. Reid Cushman et al., *Ethical, Legal and Social Issues for Personal Health Records and Applications*, 43 J. BIOMEDICAL ETHICS S51, S51 (2010) (“Unauthorized access and disclosure of health information can result in insurance and employment discrimination, as well as embarrassment and other dignitary harms.”).

135. See generally Ronen Avraham, Kyle D. Logue & Daniel Schwarcz, *The Anatomy of Insurance Anti-Discrimination Laws* (Univ. Mich. Law Sch. Pub. Law & Legal Research Paper Series, Paper No. 12–107, 2002).

136. See generally Heather Stuart, *Mental Illness and Employment Discrimination*, 19 CURRENT OP. PSYCHIATRY 522 (2006).

137. See LARSON ON EMPLOYMENT DISCRIMINATION § 170.03 (2013).

138. See generally Amanda L. Laedtke et al., *Family Physicians’ Awareness and Knowledge of the Genetic Information Non-Discrimination Act (GINA)*, 21 J. GENETIC COUNSELING 345 (2012) (studying physicians’ knowledge of protections provided to patients through the Genetic Information Nondiscrimination Act of 2008, Pub. L. No. 110–233, 122 Stat. 881, codified in scattered sections of 29 U.S.C. and 42 U.S.C.).

139. Thomas C. Buchmueller, *Marital Status, Spousal Coverage, and the Gender Gap in Employer-Sponsored Health Insurance*, 33 INQUIRY 308, 308 (1996).



Americans with Disabilities Act of 1990<sup>140</sup> and the Genetic Information Nondiscrimination Act of 2008.<sup>141</sup>

These Acts, for example, provide a check on employers' ability to use preemployment medical screenings to help determine which potential employees they should hire.<sup>142</sup> Even when employers can use preemployment screenings, however, studies evaluating whether those medical screenings provide any benefit to the employers who use them have proven inconclusive.<sup>143</sup> Because these specific discriminatory tactics may provide little, if any, financial benefit, and other statutes protect employees from similar discrimination, any privacy protections wrapped up in the regulation of health information provide only redundant protection at best. Meanwhile, that redundant protection comes at the cost of creating unnecessary restrictions and uncertainty.

Direct employment discrimination is not the only concern that comes with opening up the flow of health information, however. Costs inherent in employer-based insurance models create another source of discrimination.<sup>144</sup> The cost-benefit analysis that an employer engages in when hiring or replacing an employee is necessarily tied up with health care costs because employers consider the costs of covering an individual's insurance policy. All things being equal, then, an employer would prefer to hire the candidate who carries the lower health insurance price tag.<sup>145</sup> And although HIPAA rightfully regulates this type of discrimination, employers have turned to even more covert means of reducing health insurance costs, such as by offering insurance plans that disproportionately shift the costs of insurance onto employees with higher health costs.<sup>146</sup>

The way to prevent this type of discrimination, however, is to go straight to the source. Employers who utilize this type of discrimination try to shift costs regardless of the underlying reasons that one employee's health costs are higher than another's.<sup>147</sup> The employer in this scenario, therefore, has no need to understand the underlying reasons behind each employee's insurance premiums. Regulating health data to prevent this discrimination is therefore a misplaced means for accomplishing a legitimate end. Instead of limiting access to information, regulations should target all types of discrimination explicitly and directly.

On a more personal level, there may be certain health conditions that individuals wish to hide from family, friends, or associates. Creating extensive

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140. 42 U.S.C. §§ 12101–12300 (2012).

141. 29 C.F.R. § 1635.1–.12 (2010).

142. See NORASHIKIN MAHMUD ET AL., COCHRANE COLLABORATION, PRE-EMPLOYMENT EXAMINATIONS FOR PREVENTING OCCUPATIONAL INJURY AND DISEASE IN WORKERS (REVIEW) 3 (2010).

143. See, e.g., *id.*

144. See generally Mary Crossley, *Discrimination Against the Unhealthy in Health Insurance*, 54 U. KAN. L. REV. 73 (2005).

145. See *id.* at 75.

146. *Id.* at 76.

147. *Id.* at 75–76.

regulations to guard against the dissemination of truthful information is grounded in the idealization of human dignity.<sup>148</sup> Applying the concept of human dignity to difficult policy decisions, however, has proven troublesome.<sup>149</sup> In defamation law, for example, freedom of speech is a higher priority than preventing the dissemination of offensive information, even when that information is *untruthful*.<sup>150</sup> When true information is shared, the First Amendment provides even stronger, almost impenetrable, protection.<sup>151</sup> Because of the inherent uncertainty and subjective nature of human dignity, despite its emotional and political appeal, it is “not an effective policy tool with which to attack” troublesome health care technologies.<sup>152</sup> These same uncertainties have led federal courts to consistently reject the adoption of a federal doctor–patient privilege.<sup>153</sup>

Furthermore, studies have shown that there is a great deal of uncertainty surrounding which information consumers and patients believe should be protected, and why that information should be protected.<sup>154</sup> If consumers themselves are uncertain about what their privacy concerns are or why they have them, policymakers’ attempts to alleviate those concerns are, at best, a shot in the

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148. David A. Hyman, *Does Technology Spell Trouble with a Capital “T”?: Human Dignity in Public Policy*, 27 HARV. J. L. & PUB. POL’Y 3, 18 (2003).

149. *Id.*; see RICHARD A. POSNER, *THE PROBLEMS OF JURISPRUDENCE* 123 (1990) (“[I]ntangibles such as the promotion of human dignity . . . are too nebulous for progress toward achieving them to be measured.”).

150. See *N.Y. Times Co. v. Sullivan*, 376 U.S. 254, 271 (1964).

151. See *Fla. Star v. B.J.F.*, 491 U.S. 524, 538, 540 (1989) (labeling punishment for the dissemination of truthful information, even when that information was the name of a woman who was raped, as an “extreme step” and an “extraordinary measure”). *Florida Star* does note that the Court would “not hold that truthful publication is automatically constitutionally protected, or that there is no zone of personal privacy. . . .” *Id.* at 541 (emphasis added). Furthermore, *Florida Star* revolved around protection of the press, for which the Court addressed press-specific policy concerns. *Id.* at 535. But, although *Florida Star* could be construed as a case that involved an issue of “public significance,” is announcing to the community that a woman was raped really less intrusive to her privacy than the risk that her health information might be disclosed to researchers, friends, or employers? *Id.* at 536. If a rape is a matter that is of “clear” public significance, then surely the Court could provide the same protection for the free dissemination of truthful health information that can reduce costs and save lives.

152. See Hyman, *supra* note 148, at 18.

153. *Jaffee v. Redmond*, 518 U.S. 1, 10 (1996) (deciding that a psychotherapist–patient privilege was needed, whereas a doctor–patient privilege was not because any information related to physical ailments was objectively verifiable while mental ailments require a more subjective analysis based on patients’ “emotions, memories, and fears”). See also Ralph Ruebner & Leslie Ann Reis, *Hippocrates to HIPAA: A Foundation for a Federal Physician–Patient Privilege*, 77 TEMP. L. REV. 505 (2004) (arguing that the adoption of the HIPAA Privacy Rule proves that there is sufficient cause to create a new doctor–patient privilege on the federal level).

154. See, e.g., David J. Kaufman et al., *Public Opinion About the Importance of Privacy in Biobank Research*, 85 AM. J. HUMAN GENETICS 643, 649–50 (2009) (“It is striking that although 90% of respondents were concerned about protecting their privacy, less than half that many said that they feared that the data would be used against them.”).

dark. Between this consumer uncertainty and the general challenges of regulating even well-defined dignitary concerns, it is hard to see why the value of free-flowing health information should not far outweigh these nebulous anxieties.

Somehow, although we have managed to become a society that covets freedom of information as one of our greatest constitutional rights—a society where, at least federally, no doctor–patient privilege even exists because getting to the truth in court far outweighs the embarrassment a witness might suffer—we have also become a society that values secrecy over more efficient and effective health care. In the future, we should work to resolve this contradiction in favor of promoting health and social wellbeing.

### *B. Shifting the Focus to Transparency and Disclosures*

HIPAA has created a culture of fear. Despite its rather benign language, HIPAA has been interpreted and misinterpreted in a way that has chilled technological progress in health care and thoroughly confused consumers and health care providers alike. The effects of HIPAA have reached a point where even millions of dollars in economic incentives to adopt HIT have been met with tremendous hesitation. The current climate, however, is not without remedies.

First, public awareness through mutual trust is a key issue.<sup>155</sup> The discourse from public officials, HHS, legislatures, and health care providers themselves must begin to address patients' actual concerns over privacy by opening doors that will allow patients to know what their information is really being used for and why. Only after patients know what is going on can they decide for themselves what parts of the system they feel the need to control or for what issues they wish to require consent. Creating public awareness of both the benefits and the challenges of HIT is the first step toward transparency.

Revising and eliminating confusing legislation that only half-handedly focused on privacy, rather than spending untold resources trying to get the public to understand such convoluted regulations, would be an excellent second step. Although HIPAA and HITECH themselves are still valid laws, they continue to be slowly adapted, if not eroded, by subsequent regulations.<sup>156</sup> HIT is still recovering from many of the strange restrictions implemented through HIPAA,<sup>157</sup> and HIPAA's Privacy Rule, meanwhile, remains conspicuously intact.<sup>158</sup>

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155. See *supra* Part II.B.

156. See ROSENFELD ET AL., *supra* note 103, at 2 (HITECH “has fundamentally changed the HIT landscape in the United States”); see also *About ONC*, HEALTHIT.GOV, <http://www.healthit.gov/newsroom/about-onc> (last visited Oct. 2, 2013) (“ONC is the principal federal entity charged with coordination of nationwide efforts to implement and use the most advanced health information technology and the electronic exchange of health information.”).

157. See, e.g., CLIA Program and HIPAA Privacy Rule; Patients' Access to Test Reports, 76 Fed. Reg. 56712, (proposed Sept. 14, 2011) (to be codified at 45 C.F.R. Pt. 164) (“[T]his proposed rule would also amend the [HIPAA] Privacy Rule to provide individuals the right to receive their test reports directly from laboratories by removing the exceptions .

While changes to HIPAA, despite their indirect and slow nature, seem to be changes in the right direction, new regulations related to HITECH are creating new problems. Many physicians' concerns over EMR implementation, rather than being eliminated or even reduced, have now shifted to HITECH's definition of "meaningful use."<sup>159</sup> As HITECH's economic incentives disappear over time, however, the need for HIT development will remain. HHS should therefore shift its focus to the development of new regulations that focus on a different type of transparency—transparency that allows consumers to understand the flow of health information through disclosures and interactivity. By doing so, HHS could generate understanding and trust that can expand current conversations and encourage new conversations about how HIT can continue to develop over many years to come.

Third, disclosures and interactivity, in our extremely mobile society, do not mean much without finding ways to fix the problems with interoperability of health information. Standardizing terminology, technology, and availability clarifies discussions and promotes the use of HIT by supporting the "seamless data flow among providers and across care settings."<sup>160</sup> There are already quite a few standards for health information. These current standards, however, are not enough. Patient care, especially in terms of the therapeutic effect of the doctor-patient relationship itself, has an inherently subjective element to it that cannot always be broken into black and white categories or numerical codes. By beginning a national discourse and invoking the advice and wisdom of doctors of all different specialties throughout the country, we can begin to understand and shape an efficient health information language that toes the line between objective data and personalized care.<sup>161</sup> That language, if implemented consistently between all HIT systems, would help improve access to valuable information by health care providers, patients, and even researchers and other third parties.

These changes can help foster new, more informed conversations through a renewed effort to enhance transparency. Those conversations may lead to new developments in patient control, informed consent, and other pressing health information questions that consumers can only begin to ask after they have access to how the information system works in the first place.

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. . . from the provision that provides individuals with the right of access to their protected health information.").

158. See generally HHS OFFICE FOR CIVIL RIGHTS, *Introduction to THE HIPAA PRIVACY RULE AND ELECTRONIC HEALTH INFORMATION EXCHANGE IN A NETWORKED ENVIRONMENT* (2008).

159. See Anne Marie Valinoti, *Physician, Steel Thyself for Electronic Records*, WALL ST. J., Oct. 23, 2012, at A15; Arnold J. Stein, *Electronic Medical Records and Meaningful Use Rules*, Opinion, WALL ST. J., Oct. 31, 2012, at A.

160. Safran et al., *supra* note 122, at 2.

161. See generally Werner Ceusters, Barry Smith & Jim Flanagan, *Ontology and Medical Terminology: Why Description Logistics Are Not Enough*, in TOWARDS AN ELECTRONIC PATIENT RECORD (Medical Records Institute CD-ROM, May 2003).

### *C. Implementing Change*

If these are an ideal set of goals for jump-starting the national adoption of HIT on a much broader level, then there must also be practical ways to accomplish these goals. Private companies, to some extent, have tried to jump into the HIT battle, but without national standards for discussing and transferring health information, those private attempts have yet to meet much success.<sup>162</sup> Instead of creating arbitrary lines between what is or is not a “covered entity,”<sup>163</sup> regulations should develop a federal medical information language that will support the development of national tools for transferring and interpreting medical records. Instead of squelching private development of HIT, these new national standards could help enable it.

After health care providers have a common language to work with, they will also need a message for patients. Health care providers must be adequately informed about how health information regulations work, and they must be comfortable sharing that knowledge with their patients. The more confidence and understanding that HHS can diffuse through health care providers to patients, the more trust it can develop, and the more informed the conversation will be when HHS tackles the next set of questions: questions about consent and control.

In the meantime, to protect patients from any real risks that the disclosure of their health information might create, HHS should also develop regulations that directly target the improper *use* of health information, not the dissemination of truthful information itself. Through those regulations HHS could continue to deter discrimination or other improper uses of otherwise truthful and beneficial health information and, by doing so, continue to help foster trust and alleviate patients’ realistic concerns.

Finally, any new regulations must be accessible. As with understanding what consumers’ health information is used for, consumers also desire transparency and accessibility in the law. HIPAA is far from transparent or understandable. With a new understanding of what health information is used for, all of the social benefits that health information can promote, and the conflicting policy decisions that were carefully weighed before deciding to encourage the free flow of information, consumer trust can be promoted, not only between patients and their health care providers, but between society and the law.

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162. Even Google, the data giant, has given up on promoting electronic health record keeping. *An Update on Google Health and Google PowerMeter*, GOOGLE (June 24, 2011), <http://googleblog.blogspot.com/2011/06/update-on-google-health-and-google.html>. And Microsoft’s HealthVault, Google’s only real competition for the development of online patient health portals, may not be far behind. Brian T. Horowitz, *Microsoft HealthVault’s Survival Uncertain with Advent of GE Joint Venture*, EWEEK (Jan. 18, 2012), <http://www.eweek.com/c/a/Health-Care-IT/Microsoft-HealthVaults-Survival-Uncertain-With-Advent-of-GE-Joint-Venture-197970/>.

163. U.S. DEP’T OF HEALTH & HUMAN SERVS. OFFICE FOR CIVIL RIGHTS, *supra* note 7, at 1.

### CONCLUSION

The concept of privacy is inescapable in modern society. As technology develops rapidly and national interconnectivity becomes a part of our daily routine, the lines between what may or may not be acceptable begin to look more like curly straws than straight lines. Individual autonomy is important. We cannot, however, allow it to suffocate the advancement of technology in such vital areas as public health.

This Note cannot pretend to lay out the full route to balancing the desire for autonomy and the benefits of free information. It is merely one point of view. From this perspective, the benefits of health information technology are so extreme, and yet its progress has been so stifled, that it may be worth considering that we have placed far too much value—at least in the health care context—on individual privacy.

Bob may never know what information the internet snatched up while he was innocently clicking through the grocery store's website. Perhaps requiring the grocery store to tell him what it does with his information would be too costly, for too little benefit. We do acknowledge, however, that once Bob gets to the store, he has a strong interest in knowing what ingredients are inside each package, and how many pounds he might gain if he eats a whole container of ice cream in one sitting. The hospital's interest in getting Bob's health information as he is rolled into the emergency room is at least as strong.

Bob also has a strong interest in having access to the information that the hospital maintains about him. If that information is wrong, the results could be worse than gaining a few extra pounds. Not having the chance to ensure that the hospital knows of a past heart condition or drug allergy could kill him. And, less dramatic but more common, if Bob's information only flows one way, he remains skeptical, uncertain, and untrusting. In a profession where trust and the doctor-patient relationship are so coveted, we should promote the kind of disclosures that encourage Bob to trust his health care providers at least as much as he trusts his ice cream.